

NEWSLETTER

Caring for the Caregiver



Did you know that 75% of patient care in Ontario is provided by caregivers (The Ontario Caregiver Organization) and, for every palliative care client served at home or in a community-based hospice, five family members also receive support. In Ontario, this would translate to over 130,000 caregivers supported by hospices each year (Hospice Palliative Care Ontario - HPCO). Additionally, a Health Canada survey found that 41% of caregivers reported negative effects on their mental health, while 38% reported negative effects on their physical health. Health Quality Ontario puts the average cost to caregivers at approximately \$18,200 a month in lost wages, lost leisure time, and out-of-pocket costs.

These statistics are staggering and highlight even more the need for the Hospice Quinte Care Centre. As a caregiver, you not only carry the weight of the family, but also the overwhelming responsibility of providing end-of-life care for a loved one. For some, this leads to lack of sleep, depression, loneliness and a feeling of being trapped.

Hospice Quinte's in-home visiting volunteers provide reassurance and respite to caregivers, as well as social, emotional, and practical support.

Are you or someone you know caring for a loved one with a life-limiting illness?

Are you feeling overwhelmed, exhausted, frustrated?

Are you feeling alone or guilty you can't do more?

Do you need someone to talk to or share your experience with?

If you answered 'yes' to any of these, know you are not alone.

Our volunteers are trained extensively and understand the importance of dignity, independence, confidentiality, beliefs, choices, faith and culture. Our caregiver support programs in the new centre will help caregivers and family members along their journey, and provide a safe place to share stories with others walking the same path. These services are provided free of charge.

The new Hospice Quinte Care Centre will provide the much-needed space to build upon our existing caregiver respite programs, and introduce new services to help more individuals through a very difficult time.

Seasons Greetings

Wishing you and your family a wonderful holiday season and many blessings throughout the new year.

Please note that Hospice Quinte will be closed for the holidays beginning Tuesday, December 24 at 12:00pm and will reopen Thursday, January 2 at 9:30am.



Our Journey with Hospice

“Hospice gave me the opportunity to be a husband, not just a caregiver.”

“It is a harsh reality to realize curative medical treatment is no longer an option. Some significant events in June 2010 found us in Kingston General Hospital, seeking medical help for my wife Linda. Linda was in extreme pain and said it felt like something had broken in her back and she was losing the feelings in her legs. A doctor said to us, “We need three days to test for sure, but I would bet my house we are dealing with multiple myeloma.”



That week, surgery removed two vertebrae that had been turned to powder by the disease, causing Linda's spinal cord to be pinched. After radiation, some recovery time and treatment, still not able to walk, Linda was transferred to rehabilitation in Belleville. Eventually, she left there dependent on a walker. Later she went back to Kingston for a stem cell transplant, where her own stem cells were reintroduced to her. Chemotherapy was a part of our life until February 2018. By now, Linda was very tired and sick from the effects of the treatments and options were all but exhausted. Linda discussed her fate with doctors, wrote her obituary, made final arrangements, continued to live as best she could and still found the need or ability to make others laugh. The disease was rapidly taking its toll by the end of 2018. From that point on, trips from the house for us mostly involved doctors' visits. Then, the doctor visited us, along with PSW and nurse visits, to assist us with her personal care.

During the early part of 2018, I was introduced to Hospice. Hospice Quinte arranged regular volunteer visits to Linda and offered me opportunities during those visits to attend Caregiver Support sessions at their office.

April 2019 saw changes coming very quickly. On April 24, my 70th birthday and more importantly our 9th wedding anniversary, we installed a hospital bed. By now, Linda was not able to enjoy life events; this journey, which had not been easy for either of us during our entire marriage, was in a downward spiral.

On May 2, the Care Coordinator and Linda's doctor expressed the realization things could not continue as they had and encouraged me to consider hospice care for Linda. Linda, as did I, wanted to stay in our home until the end but Linda had charged me with making decisions for her if she was unable to. That time had come. Even with the professional help and numerous friends, I realized it would be detrimental to not take their advice. Because Belleville has no hospice beds, we went to Heart of Hastings where one was available. This was my first exposure to a hospice home. Although it was a very wonderful experience, it would have been even better, for many reasons, to have been in our own community. A lot of her faithful friends and a Hospice Quinte volunteer continued to make the trip there for regular visits. In spite of the geographical inconvenience and distance, I was able to take Linda's beloved Yorkies on regular visits with her.



About 6:30pm on June 6, 2019, almost 9 years after diagnosis, Linda took her last breath in that hospice bed. I spent a few more minutes with her and when I left the room to call her family and friends, the hospice staff lightened my load.

Hospice continued to be there for me. Though I could have attended bereavement classes in Madoc, I chose to be in my own community and participate in Belleville. Because of my age and very new and extremely altered life changes, I was very uncertain what life had left for me. Hospice Quinte was extremely instrumental in helping me find new purpose.

I have a firm conviction that hospice offers a service to a terminal patient and their family that is far beyond anything else that can be offered. Any community that can provide this service to its people can be proud.”

David M Craig

Linda's husband, from April 24, 2010 to June 6, 2019.